

Margery Miller, PhD, is a professor in the Department of Psychology and interim associate dean of the Enrollment Management and General Studies Programs at Gallaudet University in Washington, D.C.

E. Sumie Funayama, PhD, is a research consultant in physiological psychology who resides in Cincinnati, Ohio.

Right: Teens and young adults thrive on communication. Typical lunchtime scenes at the Student Academic Center lunchroom, Gallaudet University.

life after high school for deaf youth with autism:

CHALLENGES FOR STUDENTS, PARENTS, AND PROFESSIONALS

By Margery Miller and E. Sumie Funayama

Children are much more likely to be diagnosed with autism than they were 15 or 20 years ago. One possible reason, researchers speculate, is increased diagnostic precision—a widening of the autistic spectrum disorder continuum to include mildly affected children who otherwise may have gone undiagnosed and unsupported, and whose behavioral patterns may have just been viewed as “odd” or unusual (Prior, 2003; Shattuck, 2006). Others attribute the increase to environmental factors such as exposure to chemicals, infections, and dietary changes (Byrd et al., 2002; Newschaffer, Falb, & Gurney, 2005).

As understanding grows regarding the varieties of autism and autistic spectrum manifestations, so too does the assessment field—which includes psychologists, speech-language pathologists, and other health and education professionals who in many cases have expertise in deafness. The result is more children who are identified as both deaf and autistic (Yeargin-Allsop et al., 2003).

It’s hard even to estimate the number of deaf and hard of hearing children and youth with autistic spectrum disorder, but the proportion is thought to be much higher than in the hearing population. What’s more, this greater prevalence of autism in deaf children is consistent with a higher proportion of disabling conditions among the general deaf population. Estimates of the proportion of deaf children with disabilities fall between 15 and 50 percent (Davis, Fortnum, & Bamford, 1998; Holden-Pitt & Diaz, 1998; Karchmer, 1985; Mitchell, 2004). As high as it is, some researchers

Photos by John Consoli



consider this range an underestimate.

Historically, special education professionals have disagreed over designation of the primary disability of children who are both deaf and autistic. For coding and educational placement purposes, is the child deaf (primary disability coding) with autism (secondary disability coding), or is the child autistic (primary disability coding) with hearing loss/deafness (secondary disability coding)?

In recent years, the deaf child with autism most often has been regarded as a deaf special needs student. Such a designation means that the primary visuospatial communication needs of the deaf autistic child—needs that are also so important for many nonautistic deaf children—can be met by using sign language as the primary communication mode. It also means that the deaf autistic child can be supported by experts with training or experience in working with

deaf children with behavioral, intellectual, and related developmental issues (including autism).

The view that a deaf child with autism is just that—a deaf child first (because of the critical importance of communication) and an autistic child second—is the more prevalent today, especially in larger educational programs. But this was not always the case. In the past, placement decisions often were determined in the opposite way: Many deaf children with

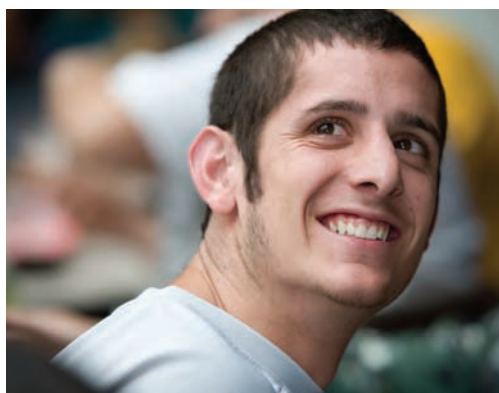


autism or other developmental disabilities were placed in programs primarily for autistic or developmentally disabled children. They were educated with peers who had normal hearing ability, and only intermittent attention was given to the deaf child's hearing loss and visuospatial orientation, communication, and language input needs, or to subsequent issues related to modality and language assessment (Pollack, 1997).

Getting Appropriate Educational Placements and Support Services: It's a Battle

Within the school system, parents are often the primary advocates for their deaf child with autism. They can spend years pursuing a proper diagnosis once they realize that their child is not keeping up developmentally with his or her "deaf-only" peers (deaf peers without developmental disabilities). This is often a time of

great disappointment and confusion for families in this situation (Wright, 2006). The parents may have already accepted that their child is deaf and concluded that being deaf is another form of normal development. They may have begun to communicate effectively with their deaf child. They may have concluded that this child who is deaf has a limitless future and will have a complete level of personal independence once he or she reaches adulthood, just as hearing children do. Then, as other deaf



children in the class continue to grow and develop, regulate their behavior, increase their interpersonal interactions, and advance in cognitive, linguistic, and academic skills, their deaf child starts to appear more and more different. Finally there comes a time when the school and the parents both come to understand that the child is not only a deaf child who requires the expertise of teachers and specialists for deaf children, but also a child who is deaf and autistic.

Parents often struggle to find the right educational placement for their deaf child with autism so that the child's communication needs are satisfied even as emphasis is placed on his or her behavioral, affective, linguistic, and learning needs. There is often a battle within the school district, especially when there are not enough deaf children with developmental disabilities to make

When a special needs class for deaf children is available, it still may take a few years before everyone understands the child's individual needs and becomes comfortable with appropriate ways to meet those needs.

a full class. The school may want to move the child from a deaf education learning environment to a placement with experts in autism and behavior management and teachers who may have



little, if any, sign language skill. Parents often resist sending their child out of a deaf-friendly learning environment, and for good reason. They want their deaf child with autism placed in a rich linguistic environment that includes sign language. They want an educational environment that will make the most of the child's learning potential and that uses a communication approach that not only enhances communication but also improves behavior, social skills, and self-regulation.

When a special needs class for deaf children is available, it still may take a few years before everyone understands the child's individual needs and becomes comfortable with appropriate ways to meet those needs. After this transition time, the child, parents, teachers, school, and program administrators most often settle into a mutually satisfying program of coordinated efforts to attain the best possible outcomes for the deaf autistic child.

However, sometime around the beginning of high school, parents once again must face the task of locating and securing services for their deaf child with autism. Are transition programs and vocational training programs

appropriate, or should the child stay in academic classes all day until graduation? Should the child graduate at age 18 and then transition to a special work or vocational training environment, or should education continue to age 21? Should parents enroll their child in a developmental program at a community college, if that option is available, or should work-related training now become the focus? A team of professionals, often called the transition team, can answer these questions in light of the student's strengths, weaknesses, and long-term needs assessment. However, parents may or may not agree, and this can be another difficult time as they fight for transition services they feel are essential to their child's success in life.

When graduation day arrives, any time between the ages of 18 and 21, families often encounter yet another challenge: locating appropriate postsecondary programs, vocational training, career coaching, and residential placement options for their deaf child (now a young adult) with autism.

Postsecondary Options for Deaf Youth With Autism

Often, each postsecondary possibility is eliminated for most deaf children with autism because of cognitive or linguistic delays, disorders sufficient to interfere with normal patterns of learning and academic achievement, and

impairments in psychosocial and behavioral functioning. Parents once again start to feel pressured and isolated as they try to set up meaningful

programs for the young adult who



is deaf and autistic.

Often, particularly in less populated areas, parents once again face the dilemma of choosing from programs that are inadequate to meet the

Putting Together or Choosing a Postsecondary Program for Your Deaf Adult Child with Autism?

HERE ARE SOME GUIDELINES.

- **Get an early start.** The process may take longer than you think. Begin searching for programs for deaf adults with autism and other developmental disabilities while your child is in junior high or the first years of high school.

- **There's lots of information out there—take advantage of it.** County, state, and federal offices can supply information about postsecondary vocational and residential programs for deaf individuals with autism. Among others, these offices can refer you to state vocational rehabilitation agencies and group home programs. Other useful sources of guidance include local, state, and national chapters of groups such as the National Association of the Deaf and state associations of the deaf. The Gallaudet University Regional Centers maintain up-to-date listings of program options in local areas.

- **Get organized.** Make copies of all pertinent records so that you can provide them to the professionals at the agencies and programs you contact. These records include transition plans, psychological assessments, medical records, and selected behavioral intervention plans and progress reports. Be sure that these records include information on “best practices”: techniques and approaches that have been most effective with your son or daughter.

- **Deal your son or daughter into the process.** To the extent that your child's intellectual and communicative capabilities permit, include him or her in discussions and planning. Your child's preferences for work and living arrangements need to be a large part of the decision-making process if you want it to succeed.

- **Get out and look around.** Visit vocational training programs and ask for a few trial days when you can observe your adult child. Or, see if you can arrange for your adult child to stay in the program for a few days without you being present in order to see if the program feels like a good fit.

- **Ask—otherwise, you'll never know.** Explore all work settings that strike you as appropriate for your deaf child with autism. Find out if employers have a history of accepting workers with disabilities, whether in supported work situations (with job coaches, for example) or nonsupported situations.

- **Help your child get mobile.** Find opportunities for your son or daughter to become a proficient user of public transportation. Greater mobility means greater independence.

- **Set your standards.** Evaluate each program on the basis of
 - Ease of communication for the deaf person with autism.
 - Frequency of signed communication and competence of sign language users in work or training environments.
 - Compatibility between behavioral, social, linguistic, and

intellectual needs and the environment.

- Availability of, or at least a willingness to include, professionals with expertise in working with individuals who are deaf and autistic so that plans, intervention programs, and assessments can be incorporated into the long-term planning for the young adult.

- Certifications granted to the program or facility and any registered violations that remain uncorrected at program entry and throughout the period of involvement with a program or agency.

- Turnover rate of clients and personnel. Residential training programs, and sometimes vocational training programs as well, tend to have high turnover rates. If that is the case for a program you're considering, find out why. If clients or staff leave to advance to better situations, that's not a problem. If they leave because of poor or inadequate programming, that should give you pause.

- **Compatibility matters.** It's preferable, of course, that your son or daughter's preferred communication mode be usable in the programs you're considering. But don't rule out programs in your area just because they may not include professionals who sign. For instance, if you want your adult child to be able to remain near the family even though no signing professionals are available in your area, see if it's possible to incorporate sign language interpreters into a local program. Your child may not be used to using sign language interpreters because there was no need for them at school. But interpreters can play a critical role in programs where no signers are present by helping your son or daughter ward off the behavioral or social difficulties that can result from communicative isolation.

- **It's OK to ask how it's going.** Once your child is in a program, request assessments at regular intervals so that you can monitor his or her progress.

- **At all levels, connect.** Cultivate a network of parents in your locality and state, and connect with national organizations as well. Start new family programs in your area and work with the local Deaf community to provide special programs, activities, and projects for meeting the needs of the deaf adult with autism and other pervasive developmental disabilities.

- **It's good to get out and play.** To enhance socialization, consider involvement in the Special Olympics if your son or daughter has an interest in competitive sports.

- **Inclusion starts with the family.** Even though your deaf child with autism is now an adult, it's important to keep him or her involved in holiday gatherings, vacations, and other family activities. To make these occasions as meaningful as possible, keep working on your sign language and behavior intervention skills.



communication needs of their young adult deaf child.

We've compiled some guidelines to help make parents in this position feel not quite so pressured, not quite so isolated (see accompanying box on page 36). These guidelines emphasize being both practical and ambitious, and, above all, stress that the young deaf person with autism is a participant in the process.

Advocacy: A Continuing Role

Parents with deaf children who are also autistic have a history of fighting for services in the schools and demanding that professionals accept sign language as a prerequisite to all other programming choices. Parents must continue to be advocates for these adult children. The good news is that they can draw upon diverse resources such as other parents, professional organizations, Gallaudet University, and local, state, and federal government agencies. Together, young deaf adults with autism, their parents, and professionals who work with people who are deaf and autistic can meet the challenge of ensuring a successful transition to a satisfying work and social life beyond high school.

References

- Byrd, R. S., et al. (2002). Report to the legislature on the principal findings from *The epidemiology of autism in California: A comprehensive pilot study*. Retrieved October 2, 2007, from a website of the California Department of Developmental Services, <http://www.dds.ca.gov/Autism/MindReport.cfm>
- Davis, A., Fortnum, H., & Bamford, J. M. (1998). Epidemiologic issues associated with newborn hearing screening. In F. H. Bess (Ed.), *Children with hearing impairment: Contemporary trends* (pp. 1–10). Nashville, TN: Vanderbilt Bill Wilkerson Center Press.
- Holden-Pitt, L., & Diaz, A. (1998). Thirty years of the Annual Survey of Deaf and Hard of Hearing Children and Youth: A glance over the decades. *American Annals of the Deaf*, 143, 72–76.
- Karchmer, M. A. (1985). A demographic perspective. In E. Cherow (Ed.), *Hearing-impaired children and youth with developmental disabilities: An interdisciplinary foundation for service* (pp. 37–56). Washington, DC: Gallaudet University Press.
- Mitchell, R. E. (2004). National profile of deaf and hard of hearing students in special education from weighted survey results. *American Annals of the Deaf*, 149, 336–349.
- Newschaffer, C. J., Falb, M. D., & Gurney, J. G. (2005). National autism prevalence trends from United States special education data. *Pediatrics*, 115, e277–282. Retrieved October 3, 2007, from www.pediatrics.org/cgi/doi/10.1542/peds.2004-1958
- Pollack, B. J. (1997). *Educating children who are deaf or hard-of-hearing: Additional learning problems* (ERIC Digest No. E548). Reston, VA: ERIC Clearinghouse on Disabilities and Gifted Education. (ERIC Document Reproduction Service No. ED414666). Retrieved October 2, 2007, from <http://www.ericdigests.org/1998-2/deaf.htm>
- Prior, M. (2003). Is there an increase in the prevalence of autism spectrum disorders? *Journal of Pediatrics and Child Health*, 39, 81–82.
- Shattuck, P. T. (2006). The contribution of diagnostic substitution to the growing administrative prevalence of autism in U.S. special education. *Pediatrics*, 117, 1028–1037.
- Tharpe, A. M. (2000). Service delivery for children with multiple impairments: How are we doing? In R. C. Seewald (Ed.) *A sound foundation through early amplification*. Proceedings of an International Conference (pp. 175–190). Stafa, Switzerland: Phonak AG.
- Wright, P. (2006). *From emotions to advocacy: The parents' journey*. Retrieved October 3, 2007, from the Wrightslaw website, <http://www.wrightslaw.com/advoc/articles/Emotions.html>
- Yeargin-Allsop, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of autism in a U.S. metropolitan area. *Journal of the American Medical Association*, 289, 49–55.